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ABSTRACT

This paper discusses the concept of individualized, supported living arrangements for individuals with severe disabilities. The supported living arrangements are intended to enable people with disabilities to live in the community in a manner of their choice that most closely approximates the experience of people without disabilities, with support and assistance in varying degrees as needed. The supported living program expects pursuit and achievement of expanded opportunities, skills, capabilities, and adaptations related to domestic, leisure, community, vocational, and other areas of life to reflect the desires and intentions of the person with disabilities. The program considers written "objectives" or "life plans" to be stigmatizing and debasing exercises. An instructional approach is maintained in all situations. Three examples are provided of young men living in single family homes in neighborhoods of their own choosing with one or two nondisabled roommates. The case examples describe financial arrangements, daily activities, and the role of the roommates. Problems in program implementation are also described, such as financial conflicts, provision of emergency services, and recruitment of companions. (JDD)

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Truly Individualized Supported Living: Utilizing Currently Available Resources to Facilitate Community Living for Persons with Challenging Behavior

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Presented at the annual conference of TASH: The Association for Persons with Severe Handicaps, San Francisco, CA, November 1992

THEMES: individualization, inclusion

Introduction.

Individuals involved in providing assistance and support to people considered to have disabilities currently face the dilemma of reversing the impact of our work over the past several decades. We put so much effort into reinforcing the concept of "exceptionality" that we now must overcome great obstacles -- most of which we ourselves created -- in order to facilitate inclusive lives for people considered to have disabilities. Often, these include unrecognized prejudices and stereotypes maintained by aspects of the status quo.

We might have built inclusive schools from the beginning. Instead, we created and continue to create increasing numbers of specific "disabilities", along with environments ("special" classes, "special" schools) and personnel for "treating" them. To bring about the re-inclusion of individuals excluded due to perceived disabilities of theirs -- rather than disabilities in our approach to educating them -- now requires extensive effort. We might have built inclusive workplaces. Instead, we created "sheltered" varieties of quasi-workplaces. Re-including those excluded now requires extensive effort.

Those of us not considered significantly disabled generally treat individualized and included living as a personal right, at least within the confines of additional determininng factors such as financial status, age, race, gender, sexual orientation, etc. Yet again, rather than building avenues to included living, we have favored "projects", "programs", and "models" of segregated living of nearly infinite varieties of elegance. Supported living can provide a way out, though like other inclusive formats it requires extensive effort.

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An enduring aspect of supported living involves continuously detecting, identifying, and resisting both subtle and blatant pressures to homogenize assistance, while recognizing that the formalized provision of assistance itself separates the assisted from everyone else. We have grown accustomed to the use of administrative convenience as a basis for decision making and to the belief and practice of measuring external aspects of other peoples' lives to determine "success". These habits have become so strong that they often impose unrecognized restraints on truly enabling the self actualization of people considered to have disabilities.

Funding sources want "accountability", so we save and dutifully photocopy and submit grocery store receipts. Yet, few of us systematically retain our personal grocery receipts beyond taking the opportunity to review them for accuracy; fewer still would dream of showing them to others for their review. "Case management" agencies want individualized plans with measurable objectives, so we glibly agree to offer a person "five opportunities each week to participate in specific leisure activities." Many of us would feel sorely tempted to do bodily harm to an acquaintance who persisted at such behavior. Families want access, supervision, and on site inspection, often ignoring the fact that these very things typically set the stage for parent/child conflict during the years a child lives at home and most of us treasure the control over these we establish by eventually "leaving the nest" and taking our own place in the world. We believe we have just begun to develop understandings of these many "institutionalizing" attitudes and formats.

Due in part to our overall committment to individualization, we hesitate to propose a definition of supported living. The following excerpt from some recent correspondence fairly characterizes our overall philosophy.

"We intend the supported living arrangements we coordinate to assist people [considered to have] . . . disabilities to live in the community in a manner of their choice that most closely approximates the experience of people not considreed to have disabilities. We intend support and assistance provided a person with disabilities as no more that extensions by degree of the support and assistance available to all individuals by others paid or not to provide such support and assistance. We expect pursuit and achievement of expanded opportunities, skills, capabilities, adaptations, etc. related to domestic, leisure, community, vocational, and other areas of life to reflect the desires and intentions of the person considered to have disabilities. Part of our job involves devising means of assisting people to communicate to us their desires and intentions. Secondarily, we take into consideration information provided by others familiar with the person that in our view clearly reflects the actual best interests of the person with disabilities as opposed to some amount of self interest on the part of the person providing the information.

We may develop written "objectives" or "life plans" only insofar as required by funding or other regulatory agencies; we consider such materials and such an approach inherently debilitating as an extraordinarily stigmatizing and debasing exercise worth avoiding as much as possible. We ardently trust the power and utility of attending to the business of insuring that people with disabilities have maximum exposure to all of the many activities and opportunities of daily life that present themselves in the natural course of living in a situation specifically designed as unrestricted by considerations of a person's "disability". We maintain an instructional approach . . . in all situations, in a continuous effort to assist others to explore and experience new things and to develop greater competencies to enable each person increasingly expanded choices of ways to maintain and enhance her/his own life experience." At the same time, we try to learn from our experiences with people considered to have disabilities.

Examples.

Each of these young men live in single family homes in neighborhoods of their own choosing with one or two roommates not considered disabled. The funding agency that pays for traditional group home residence agreed to contract with B*E*T*A for an amount of financial support equal to what it had previously cost to provide a residence for each of these young men within that format. It bears noting here that each of these young men had consistently previously met failure at this level of support. Additional financial support, if any, comes from a program called In Home Supportive Services, originally intended to provide attendant and other assistive services to people facing physical challenges. Each young man pays personal living expenses such as rent, utilities, food, and incidentals from his personal resources, typically Supplemental Security Income.

1. Richard previously lived in group homes of various sizes. Those responsible for the residences had asked him to leave each of these because he would sometimes spend periods of time talking loudly enough to be felt to be aversive by others, often continues talking at great length about a single topic, occasionally would bang on or move objects in the home in such a way that they could become broken, occasionally would urinate in places other than the toilet, and occasionally would verbally threaten self harm. Richard spent interim periods living with one of his parents, which neither they nor he found tolerable.

   Richard manages most of his daily activities himself, such as bathing, dressing, some food preparation, use of public transportation, leisure pursuits, and some shopping. He spends his daytime hours at a large segregated site that provides arts and crafts and some vocational activities. His time at this varies because he chooses not to attend or his supervisors require him not to attend for periods of time.

Today, Richard lives in a two bedroom rented home with a large back yard on a quiet tree lined street. Jim, a slightly older man not considered disabled, lives together with him. They share household expenses and duties equally. Jim also maintains responsibility for general oversight and some instruction, although Richard recently demonstrated great facility dealing alone with a household emergency, a sewage problem in the front yard requiring contact with the property owner and the repair people. Richard still does some of the things that got him evicted from previous traditional group home settings, but we of course expect continued improvement. Most importantly to us, he also regularly speaks, quite adamantly, about "my house!"

Budget: (MONTHLY)

Amount available from funding agency (R.C.) (equivalent to expense of previous traditional group home settings; applicable only to support services direct costs)	$ 2,534.00

Expenses --

Salary of Primary Companion	1,500.00
Benefit Allowance	120.00
Wages of Alternate Companions	300.00
Payroll Taxes, Insurance, Etc.	250.00
Program Coordination, Supervision, Expert Consultation, Etc.	355.00
TOTAL:	$ 2,530.00

Personal Living Expenses --
(managed in house by Richard and Jim)

Rent	700.00
Utilities	150.00
Food, household, incidental	500.00
TOTAL:	$ 1,350.00

Richard's Income --

(responsible for half of above)	700.00

2. Jeff previously lived in group homes of various sizes, and even participated in a nontraditional supported living variant that included two people considered to have disabilities but who had not specifically chosen to live together. Those responsible for these residences had asked him to leave each because he would sometimes spend periods of time talking loudly enough to be felt to be aversive by others, sometimes would repeat one or more questions a large number of times, sometimes would bang on or move objects in the home in such a way that they could become broken, and occasionally would verbally threaten self harm,

strike his own head with his hands, and/or strike his head against a nearby hard surface. Jeff spent interim periods living with his parents, which proved intolerable for both them and him.

Jeff manages most of his daily activities himself, such as bathing, dressing, some food preparation, laundry, use of public transportation, some shopping, leisure pursuits, and even riding a motorcycle. A supported employment program he attended recently suspended him until they can develop the capability to provide one to one support. This suspension has so far lasted for several months.

Today Jeff lives in a two bedroom rented home in an upscale suburban development. His home has a large back yard and sits across from a large open green space. Dennis, a slightly older man, and another friend, neither considered to have disabilities, live with Jeff. They share household expenses equally. Dennis maintains responsibility for general oversight and instruction. Jeff continues to make progress overcoming some of the old habits that resulted in his eviction from previous residences.

Budget: (MONTHLY)

Amount available from funding agency (R.C)	$ 2,440.00
Expenses --	
Salary of Primary Companion	1,700.00
Benefit Allowance	120.00
Payroll Taxes, Insurance, Etc.	200.00
Program Supervision, Etc.	380.00
TOTAL:	2,400.00

Personal living expenses approximate example 1 above.

3. Deron previously lived in traditional group homes of various sizes. Those responsible for these residences had asked him to leave each because he would often spend periods of time making noises found aversive by others, often would strike out at, pinch, scratch, and/or bite others, and often would strike at his own neck, face, and head with his hands. Deron spent interim periods of time living with his parents, which proved difficult for both him and them.

Deron manages almost none of his daily activities. During the day on weekdays, he has a specially developed entirely community based school program conducted by a specially trained implementer.

Today Deron lives in a three bedroom rented home with a large deck and back yard, in an upscale suburban development. Jason, a young man Deron's age, and a friend of Jason's, neither considered to have disabilities, live with Deron. They share household expenses equally. Jason maintains responsibility for general oversight and ongoing instruction, recreation, transportation, etc. Deron's parents currently administer the financial and companionship arrangement with Deron's live in companions and others who assist at various times (Alternate Companions).

Budget: (MONTHLY)

Amount available from funding agency (R.C.)	$ 2,863.00
Amount available for In Home Supportive Services (I.H.S.S.)	1,000.00
TOTAL:	3,863.00

Expenses:

Salary of Primary Companion ($1,261.00 R.C. plus $714.00 I.H.S.S.)	1,975.00
Benefit Allowance (R.C.)	120.00
Wages of Alternate Companions ($528.00 R.C. plus $272.00 I.H.S.S.)	800.00
Payroll Taxes, Insurance, Etc. (R.C.)	300.00
Reimbursable Companion Expenses (R.C.)	220.00
Program Supervision (R.C.)	430.00
TOTAL:	$ 3,859.00

(R.C.: $2,859.00 plus I.H.S.S.: $1,000.00)

Personal living expenses approximate example 1 above.

Arrangements.

The specifics of companionship for each of these young men differs according to each situation, the desires of each, and changes we see over time. Deron has one or more companions with him at all times, day or night, within his home and/or at activities in the community. Thus, Jason's partner sometimes assumes responsibility as an Alternate Companion, and as many as three other people assist in this way. Deron's parents remain available for him to visit, and live within walking distance. The frequency of these visits, however, continues to decrease. People who provide companionship for Deron must become familiar with the specific facilitated communication materials he uses, which themselves continue to evolve over time. And, as mentioned, Deron's parents currently administer the financial and companionship arrangements involved in assisting him to successful supported living.

We continue to explore additional funding resources, such as "follow along" money provided for individuals leaving an institution.

Jeff spends a great deal of his time alone and/or with his own friends at home or out in the community. Dennis and he share specific activities such as household chores, household shopping, bill paying, and periodic dinners out with or without other friends. The fact that another roommate not considered to have disabilities lives with Jeff and Dennis, but has no specific relationship with B*E*T*A, helps to reduce somewhat the share of household expense that Jeff must bear and provides some additional social, personal, and emotional support for Dennis. Jeff visits with his parents, who live a short bus ride away, several times monthly, sometimes for an entire weekend. In general, Primary Companions and the people considered to have disabilities whom we support make arrangements directly with Alternate Companions according to guidelines provided them by B*E*T*A. Though they do have this capability, neither Dennis nor Jeff involve Alternate Companions on any regular basis, partially because of the ready availability of natural unpaid supports.

Richard seems to have determined that he wants to live entirely alone. He regularly refuses invitations to visit his family, a short bus ride away, declines the companionship of an Alternate Companion, and requests that his Primary Companion spend time elsewhere. We have begun attempting to determine how we might simultaneously address the issues of personal living expenses for Richard, maintaining a reasonably safe situation, and providing Jim with nearby comfortable places to spend his time.

Complications.

Besides the continuous pressure to allow a "model" to develop, we have faced a few quite challenging complications that cut across all three of the above arrangements and others currently developing.

Money and related matters provide ongoing opportunities for misunderstandings and conflict. This includes such things as who pays for what; access and documentation that does not demean the person considered to have disabilities, does not prove extraordinarily cumbersome for the Companions, and maintains enough oversight that all may feel comfortable; and, living within a fairly tight budget.

Provision of "fall back" and/or emergency services has proven somewhat difficult. In emergencies, which have occurred only very infrequently, (two in a total of 20 months of supported living) we rely on publicly available services such as 911, on parents and other family members, and on relationships developed with neighbors. We expect the Primary Companion or an Alternate Companion present in her/his stead to assume primary responsibility for handling emergency and near emergency situations, but at least two of the young men we now assist spend significant amounts of time without any sort of paid companion present.

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Another sort of "fall back" issue assumes precedence at times when a Companion cannot or wishes not to provide assistance or to continue to provide assistance. We first turn to available Alternates. However, we have had some difficulty recruiting and securing people to serve as Companions who meet our standards for integrity, sensitivity, autonomy, honesty, dependability, an ability to follow guidelines precisely, and an ability to maintain accurate records. Thus, sometimes we have no recourse and cannot provide companionship. This situation affects perceptions of the permanence of supported living arrangements. We hope that as supported living services in our area expand and become familiar we will develop increasing ability to draw upon a larger pool of employment candidates. In most instances, the person's family remain the service supports of last resort.

Most of the families with which we have become involved so far have viewed supported living as exactly similar to a group home arrangement but on a smaller scale. Significant energy and effort continues to go into educating everyone involved; we have made very slow progress here.

- - E N D - -

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Examples.

Each of these young men live in single family homes in neighborhoods of their own choosing with one or two roommates not considered disabled. The funding agency that pays for traditional group home residence agreed to contract with B*E*T*A for an amount of financial support equal to what it had previously cost to provide a residence for each of these young men within that format. It bears noting here that each of these young men had consistently previously met failure at this level of support. Additional financial support, if any, comes from a program called In Home Supportive Services, originally intended to provide attendant and other assistive services to people facing physical challenges. Each young man pays personal living expenses such as rent, utilities, food, and incidentals from his personal resources, typically Supplemental Security Income.

1. Richard previously lived in group homes of various sizes. Those responsible for the residences had asked him to leave each of these because he would sometimes spend periods of time talking loudly enough to be felt to be aversive by others, often continues talking at great length about a single topic, occasionally would bang on or move objects in the home in such a way that they could become broken, occasionally would urinate in places other than the toilet, and occasionally would verbally threaten self harm. Richard spent interim periods living with one of his parents, which neither they nor he found tolerable.

   Richard manages most of his daily activities himself, such as bathing, dressing, some food preparation, use of public transportation, leisure pursuits, and some shopping. He spends his daytime hours at a large segregated site that provides arts and crafts and some vocational activities. His time at this varies because he chooses not to attend or his supervisors require him not to attend for periods of time.

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Today, Richard lives in a two bedroom rented home with a large back yard on a quiet tree lined street. Jim, a slightly older man not considered disabled, lives together with him. They share household expenses and duties equally. Jim also maintains responsibility for general oversight and some instruction, although Richard recently demonstrated great facility dealing alone with a household emergency, a sewage problem in the front yard requiring contact with the property owner and the repair people. Richard still does some of the things that got him evicted from previous traditional group home settings, but we of course expect continued improvement. Most importantly to us, he also regularly speaks, quite adamantly, about "my house!"

Budget: (MONTHLY)

Amount available from funding agency (R.C.) (equivalent to expense of previous traditional group home settings; applicable only to support services direct costs)	$ 2,534.00

Expenses --

Salary of Primary Companion	1,500.00
Benefit Allowance	120.00
Wages of Alternate Companions	300.00
Payroll Taxes, Insurance, Etc.	250.00
Program Coordination, Supervision, Expert Consultation, Etc.	355.00
TOTAL:	$ 2,530.00

Personal Living Expenses --
(managed in house by Richard and Jim)

Rent	700.00
Utilities	150.00
Food, household, incidental	500.00
TOTAL:	$ 1,350.00

Richard's Income --

(responsible for half of above)	700.00

2. Jeff previously lived in group homes of various sizes, and even participated in a nontraditional supported living variant that included two people considered to have disabilities but who had not specifically chosen to live together. Those responsible for these residences had asked him to leave each because he would sometimes spend periods of time talking loudly enough to be felt to be aversive by others, sometimes would repeat one or more questions a large number of times, sometimes would bang on or move objects in the home in such a way that they could become broken, and occasionally would verbally threaten self harm,

strike his own head with his hands, and/or strike his head against a nearby hard surface. Jeff spent interim periods living with his parents, which proved intolerable for both them and him.

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Benefit Allowance	120.00
Payroll Taxes, Insurance, Etc.	200.00
Program Supervision, Etc.	380.00
TOTAL:	2,400.00

Personal living expenses approximate example 1 above.

3. Deron previously lived in traditional group homes of various sizes. Those responsible for these residences had asked him to leave each because he would often spend periods of time making noises found aversive by others, often would strike out at, pinch, scratch, and/or bite others, and often would strike at his own neck, face, and head with his hands. Deron spent interim periods of time living with his parents, which proved difficult for both him and them.

Deron manages almost none of his daily activities. During the day on weekdays, he has a specially developed entirely community based school program conducted by a specially trained implementer.

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Budget: (MONTHLY)

Amount available from funding agency (R.C.)	$ 2,863.00
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Expenses:

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Program Supervision (R.C.)	430.00
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(R.C.: $2,859.00 plus I.H.S.S.: $1,000.00)

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Arrangements.

The specifics of companionship for each of these young men differs according to each situation, the desires of each, and changes we see over time. Deron has one or more companions with him at all times, day or night, within his home and/or at activities in the community. Thus, Jason's partner sometimes assumes responsibility as an Alternate Companion, and as many as three other people assist in this way. Deron's parents remain available for him to visit, and live within walking distance. The frequency of these visits, however, continues to decrease. People who provide companionship for Deron must become familiar with the specific facilitated communication materials he uses, which themselves continue to evolve over time. And, as mentioned, Deron's parents currently administer the financial and companionship arrangements involved in assisting him to successful supported living.

We continue to explore additional funding resources, such as "follow along" money provided for individuals leaving an institution.

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Richard seems to have determined that he wants to live entirely alone. He regularly refuses invitations to visit his family, a short bus ride away, declines the companionship of an Alternate Companion, and requests that his Primary Companion spend time elsewhere. We have begun attempting to determine how we might simultaneously address the issues of personal living expenses for Richard, maintaining a reasonably safe situation, and providing Jim with nearby comfortable places to spend his time.

Complications.

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Money and related matters provide ongoing opportunities for misunderstandings and conflict. This includes such things as who pays for what; access and documentation that does not demean the person considered to have disabilities, does not prove extraordinarily cumbersome for the Companions, and maintains enough oversight that all may feel comfortable; and, living within a fairly tight budget.

Provision of "fall back" and/or emergency services has proven somewhat difficult. In emergencies, which have occurred only very infrequently, (two in a total of 20 months of supported living) we rely on publicly available services such as 911, on parents and other family members, and on relationships developed with neighbors. We expect the Primary Companion or an Alternate Companion present in her/his stead to assume primary responsibility for handling emergency and near emergency situations, but at least two of the young men we now assist spend significant amounts of time without any sort of paid companion present.

Another sort of "fall back" issue assumes precedence at times when a Companion cannot or wishes not to provide assistance or to continue to provide assistance. We first turn to available Alternates. However, we have had some difficulty recruiting and securing people to serve as Companions who meet our standards for integrity, sensitivity, autonomy, honesty, dependability, an ability to follow guidelines precisely, and an ability to maintain accurate records. Thus, sometimes we have no recourse and cannot provide companionship. This situation affects perceptions of the permanence of supported living arrangements. We hope that as supported living services in our area expand and become familiar we will develop increasing ability to draw upon a larger pool of employment candidates. In most instances, the person's family remain the service supports of last resort.

Most of the families with which we have become involved so far have viewed supported living as exactly similar to a group home arrangement but on a smaller scale. Significant energy and effort continues to go into educating everyone involved; we have made very slow progress here.

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